I AM ALS

Get In. We're Ending ALS

What We're Up To

Forgive us for repeating ourselves, but it's just such good news – the second Advisory Committee meeting (AdCom) for AMX0035 resulted in a 7 - 2 vote in favor of approval! The FDA now has until September 29 to decide whether or not to approve AMX0035 for the treatment of ALS. While these AdCom results don't guarantee approval, they represent a big step forward, and a vote of confidence for the drug's effectiveness.

Check Out the ALS Calendar

Looking for ALS events near you? Hosting one yourself and want the world to know? Amazing volunteer Rob Faulstich has been populating the ALS calendar with incredible events – check it out and share it with your networks!

TAKE A PEEK

COMMUNITY UPDATES

Clinical Trials Team

This team is dedicated to carrying on Sandy Morris' legacy. Sandy was a former co-chair and founding member. To do this, they want you to know about the Patient-Centric Trial Design (PaCTD) Rating System for ALS clinical trials. Learn more here, and if you see an ALS clinical trial that needs a PaCTD rating, let us know!

Community Outreach Team
This team wants you to know about the shiny new landing page for the Ask Me Anything ALS series! This page is your one-stop shop for all the videos and resources that have come out of past AMA events, as well as a place to track upcoming events and topics. Check it out **here**, and if you have a suggestion for a future Ask Me Anything topic, let us know!

Familial ALS Team
This team is excited to host Claire Clelland, PhD, MD, MPhil for a conversation on the process of developing a gene therapy and what is on the horizon for C9 CRISPR gene editing. RSVP **here**!

Legislative Affairs Team
As part of the implementation of ACT for ALS, the FDA and NIH have launched a public-private partnership for rare neurodegenerative diseases! This partnership is "aimed at… fostering the development of treatments for amyotrophic lateral sclerosis (ALS) and other rare neurodegenerative diseases." Read more about this **here**.

Many Shades of ALS Team
In honor of Hispanic Heritage Month, this team is hosting a community conversation on language and access next Monday! This will be conducted in Spanish and English and will address language-based barriers to ALS care. RSVP for this important event **here**.

Veterans Team
These advocates have been hard at work producing some incredible resources for veterans and their loved ones! They've created a **VA checklist for veterans** living with ALS, and a **planning guide for loved ones** of veterans living with ALS.

COMMUNITY SUPPORT CORNER

The Peer Support Initiative (PSI) at IAA is seeking more mentors who are living with familial forms of ALS with known genetic variants. If you are part of an ALS family and have been diagnosed with ALS, we'd be grateful and honored to have you be part of this program. Through the PSI, we seek to reduce feelings of isolation, improve coping skills, and increase hope by connecting people who've been impacted by ALS with peer mentors to provide 1:1 support. Apply to be a mentor **here**.

In Memoriam: Sandy Morris

There are no words to describe the magnitude of this loss. Sandy helped found I AM ALS and built it from the ground up. She has been with us since the beginning, as a friend, collaborator, cheerleader, and doer. Sandy made everyone feel loved and cared for, from her family to her co-collaborators to people she had just met, but she was also our "honey badger" – she wouldn't take no for an answer, from Congress, the FDA, drug companies, or anyone who stood in the way of care and therapies for ALS. We miss her so, so much. Read Sandy's story in her own words **here** and her obituary **here**.

In Memoriam: Taya Jones

It is with deep sadness that we also announce the passing of Taya Jones. Taya had a sparkling personality and dazzling smile that she brought with her everywhere – including to the jumbotron at the Toronto Blue Jays' Lou Gehrig Day event. Taya leaves behind her children and a massive network of family and friends who deeply adored her. Read Taya's story in her own words **here**, and a moving article about her **here**.

WHAT'S COMING UP?

Ask Me Anything ALS - Caring for a Parent

When a parent is diagnosed with ALS, we face the painful reality of losing our lifelong cheerleader earlier than we expected. On top of this grief lies the decision of how to best care for your parent as their ALS progresses. Attempting to cope with all of this while seeing to existing demands in your life can sometimes turn your world upside-down. Join I AM ALS community members and Sarah Trott of Sarah's Caregiving Community at this event on September 27th at 6 p.m. ET to discuss the nuances of caring for a parent living with ALS.

Register

Hispanic Heritage Month Social Hour

Want to meet other Hispanic people living with and impacted by ALS? We're glad you found us! I AM ALS, the I AM ALS' Many Shades of ALS team, and ALS Association Golden West Chapter are honoring and celebrating Hispanic Heritage Month with a Hispanic Heritage Month Social Hour in Spanish on October 6th at 6 p.m. ET! This informal get together will be hosted on Zoom and like all I AM ALS events, the community drives the agenda, so bring some topics or questions you want to discuss.

Register

ALS Town Hall - Meet Your ALS Orgs #2

This webinar series from ALS TDI has created a platform for the ALS community to meet some of the key people in the different ALS organizations that form our community and learn about the work that they are doing. On September 27 at 4 p.m. ET, you'll hear from the following organizations: ALS Therapy Development Institute (ALS TDI), ALS MND Alliance, Compassionate Care ALS, Project ALS, and Your ALS Guide.

Register

SEE ALL EVENTS

I AM ALS is a patient-led community that provides critical support and resources to patients, caregivers and loved ones. It empowers advocates to raise awareness and lead the revolution against ALS in driving the development of cures. Learn more at **iamals.org.**

I AM ALS

1200 Pennsylvania Ave NW, #14135 Washington, DC 20044